Alabama Interagency Autism Coordinating Council (AIACC) Monday, January 28, 2019 Alabama Industrial Development Training Center

The AIACC met on Monday, January 28, 2019, at the Alabama Industrial Development Training Center. The meeting was called to order by Co-Chair, Whitney Meade. Also in attendance were Council members: Fred Biasini, Brooke Bowles, Jane Elizabeth Burdeshaw, Robert Caldwell, Tametria Conner, Suzanne Dowling, Megan Everett, Erich Grommet, Heather Jones, Melanie Jones, Constance Rice Johnson, Justin Schwartz, Chris Stewart, and Karen Willis. The following proxies were in attendance as well: Beverly Churchwell on behalf of Stephanie Azar, Jeff Williams on behalf of Lynn Beshear, Sabrina Franks behalf of Nancy Buckner, Nancy Thomas on behalf of Lucian Cronkite, Laurie Eldridge-Auffant on behalf of Scott Harris, Sophia Whitted on behalf of Myra Jones, Vera Hendrix on behalf of John Mascia, Yada Horace on behalf of Jim Ridling, and Dianna Tullier on behalf of Jeana Ross. Also in attendance was Anna McConnell, State Autism Coordinator.

The minutes from the October 15, 2018 meeting were approved and adopted.

Co-Chair Comments: Whitney Meade welcomed attendees to the AIACC meeting.

Lead Agency Comments: Jeff Williams welcomed audience on behalf of ADMH.

State Coordinator Comments: The legislative session will begin March 5 and go until May 3.

New Business:

Anna McConnell shared progress and opportunities for contributing to the AIACC Strategic Plan. See Attachment A for guiding document for how to contribute to the Strategic Plan's activities. Objectives were identified based on the UAB School of Public Health's work on the Rapid Autism Needs Assessment and Environmental Scan (presentation). Subcommittee's recommendations for activities to include in the AIACC Strategic Plan are due March 15. The information will be compiled and submitted to the AIACC vote on April 1, with the vote taking place during the April 15 AIACC meeting.

Angie Barber discussed progress toward identifying screening and interventions specific for autism that could be delivered through Part C. They are also looking at how this would be planned for, in consideration of other services that are anticipated to come on board. A set of service guidelines will be forthcoming from this group. Also, the work that is being done through this workgroup, in partnership

with AIACC, would fit nicely in relation to the AIACC Strategic Plan. We plan for this to be a collaborative work that could overlay with the work of the AIACC.

Public Awareness: Melanie Jones and Brooke Bowles updated the group regarding the Autism Friendly initiative. They are currently working on web and graphic design and videography. Over the next 2 years, they are looking to working 50 businesses. An autism friendly training will be available on the ASA website soon. In order to participate, businesses must hire an employees or volunteer with ASD.

Regional Autism Networks:

<u>Auburn</u>: Doris Hill presented and exhibited at a number of conferences and plans on hosting a coffee chat in February in Ozark, AL. She and other RANs will be presenting at DHR's Adult Protective Services <u>University of Alabama</u>: Sylvia Hollins participated in several trainings for prek-12th grade educators, trainers, and coaches. She has also been doing a lot of outreach to all DHR Offices in the 13 counties in UA's region. Presentations have also be given at Children's Policy Councils in multiple counties. She expressed her thanks for the response from social workers at DHR in particular. The first parent education workshop will be February 12 in Tuscaloosa, and in partnership with Autism Society of Alabama. The topic will be Autism 101 presented by Dr. Angie Barber, Chair of UA's Speech and Hearing Department.

<u>University of Alabama at Birmingham</u>: Elizabeth (Lizzie) Griffith shared about the Community Education Workshops that had been held (topics include long-term planning, sleep, and challenging behavior). DMH and the RANs are applying for a grant from HRSA for Innovative Care Coordination for Children with ASD and other Developmental Disabilities, and which focuses on provider education and family navigation (care coordination).

<u>University of Alabama in Huntsville</u>: Whitney Meade reported on teacher training that is upcoming in the spring. The Taboo Topics conference with Stephen Shore and Alex Plank saw 200 attendees.

<u>University of South Alabama</u>: Amy Mitchell welcomed Constituency Board member Melanie Shong Helm. Five of the 10 counties served by the USA RAN are represented by the Constituency Board at this time.

Funding and Finance:

Elizabeth Griffith introduced the funding request for RANs, that requested a doubling of funds for RAN sites (increase to \$150k), or at minimum, increase to \$100k per university. See Attachment B for the Funding Request, submitted by the RAN Committee, which was approved by the Funding and Finance Committee. Co-Chair Whitney Meade opened the opportunity for the AIACC to vote to approve this request. It passed with none opposed.

Commissioner Burdeshaw of Alabama Department of Rehabilitation Services addressed the group regarding a funding request for the Early Intervention Services, which serves the Birth to 3 eligible population. There has been an increase in the number of children who need special services for deafness and ASD who served by Early Intervention. Over the last decade, the number of children served has doubled to 8,000, without an increase in federal funding. Early Intervention provides services in the natural environment. Commissioner Burdeshaw reported that roughly 98% of all funds go to direct services. The request is being made for additional funds this legislative session. See the <u>flyer</u>. Commissioner Burdeshaw also noted that it is difficult to meet needs for those with deafness or blindness and co-occurring ASD. Ms. Vera Hendrix also noted that AIDB works to serve this population and sees the difficulties as well. Trainings and programs for teachers are needed.

Updates:

Behavior Analyst Licensing Board: Heather Jones gave the update for the Behavior Analyst Licensing Board. Another 10-12 applicants were licensed during the last quarter. The Board will also be making recommendations to the Governor for an opening position as another member rolls off.

Update on Private Coverage for ASD: Nancy Thomas of New Directions Behavioral Health noted that less than 100 BCBAs are credentialed through their program. She brought a handout regarding provider enrollment and training was made available at the AIACC meeting. Questions were raised regarding the process to become credentialed. It was noted that ALLKids needed more BCBAs enrolled too.

Public Coverage of ASD: Nancy Anderson of Alabama Disabilities Advocacy Program (ADAP) noted that updates have been vague due to potential litigation. Program specifications are still being completed. The anticipated services are: Intensive Care Coordination, Therapeutic Mentoring, Behavior Support, In Home Therapy, Psychoeducational Services, and Peer Support. The Autism Working Group put in a tremendous amount of work for the program specifications, and it will soon be done. Reimbursement rates are not yet available, but should be posted in the Medicaid fee schedule in the Rehab Option. Beverly Churchwell of Alabama Medicaid noted that the State Plan Amendment for ASD Services was submitted on December 21. She also noted that ABA therapy should be posted in the fee schedule on AMA's website and similar to private insurance reimbursement levels. For Applied Behavior Analysis services through the EPSDT services, there have been 40 provider applications, 14 completed applications, 10 returned for corrections, and 1 PA has been submitted for review. The list of currently approved ABA providers for Alabama Medicaid is available here.

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Bama Hager from Autism Society of Alabama noted that some larger employers in AL are continuing to

choose to begin offering ABA coverage to employees. ASA is tracking reports of reimbursement

success through family contacts.

Member Updates:

Autism Society of Alabama is preparing for annual walks and Light It Up Blue campaign. There is a first

responder training in Alabaster on February 25. There is also a parent social associated with the

Alabama Autism Conference in Tuscaloosa on Feb 21.

Tametria Conner noted her work with MANE and upcoming trainings in February and March.

The AAPN will meet at Easter Seals immediately following the AIACC meeting.

Triumph Services welcomed Beth Zaiontz as the new Executive Director.

Justin Schwartz introduced Laura McGuinn, Craig Powell, and Tony Fargason from Children's of

Alabama.

Sarah O'Kelley reminded the group that early bird registration for the Alabama Autism Conference

ends January 31. Go to autism.ua.edu to view the agenda. The focus this year is on communication.

Robert Caldwell noted that he was interviewed by a local news station.

The meeting was adjourned at 12:00 p.m.

Next meeting: Monday, April 15, 2019

Recording Secretary

A. McConnell

Attachment A

Strategic Planning Draft

Instructions

The listed Objectives below were pulled from the Autism Rapid Needs Assessment and Environmental Scan (performed by UAB School of Public Health). Please keep the Objectives listed as part of the Strategic Plan, but you may edit them or add new ones as your group deems appropriate. Please use the final Needs Assessment report and corresponding presentation for reference to guide your decision making. The Themes identified in Figure 1 (page 6) of the Needs Assessment may also be turned into Objectives, Activities, or items of note as you consider what the AIACC Strategic Plan should look like moving forward.

The completed draft of each committee/subcommittee Strategic Plan section is due Friday, March 15. It will be compiled into one document, distributed for review by April 1, and voted on during the April 15th AIACC meeting. Submit to anna.mcconnell@mh.alabama.gov. Please make each activity "SMART":

- Specific target a specific area for improvement.
- Measurable quantify an indicator of progress.
- Assignable specify who will do it.
- Realistic state what results can realistically be achieved.
- Time bound specify when the result(s) can be achieved.

The AIACC has been working on a 3 year planning timeline; however, if you identify objectives that need to take longer (5 or 10 years), please provide that information and steps to achieving those objectives.

Requested	Format:
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Goal:

Objective 1:

Activity(ies)	Measurement	Date to be Completed	Responsible Party(ies)

Objective 2:

Activity(ies)	Measurement	Date to be Completed	Responsible Party(ies)

Objective 3:

Activity(ies)	Measurement	Date to be Completed	Responsible Party(ies)

Funding and Finance

Goal: Identify and analyze issues related to fiscal support of a system of care for ASD and make recommendations to the AIACC for funding strategies and requests.

Objectives:

- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease the burden of cost for caregivers and families of an individual with ASD.
- Support a system to provide respite care for caregivers and families of an individual with ASD.

Medicaid Advisory Group

Goal: Provide advice and recommendations regarding development and implementation of publicly funded service systems (namely, Medicaid) for persons with ASD.

Objectives:

- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.

Public Awareness

Goal: Raise Public Awareness of issues and needs affecting persons with ASD and their families.

Objectives:

 Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.

Standards of Practice

Ages 0-5

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Decrease the average age of initial evaluation and diagnosis for children with a concern of ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease wait-list time and increase availability/eligibility of services, such as diagnostics and mental health.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.
- Decrease the burden of cost for caregivers and families of an individual with ASD.
- Support a system to provide respite care for caregivers and families of an individual with ASD.

Ages 6-13

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Decrease the average age of initial evaluation and diagnosis for children with a concern of ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease wait-list time and increase availability/eligibility of services, such as diagnostics and mental health.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.
- Decrease the burden of cost for caregivers and families of an individual with ASD.
- Support a system to provide respite care for caregivers and families of an individual with ASD.

Ages 14-20 (transition)

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Support the transition from adolescence into adulthood at the individual and family level.
 - Educate families and school systems on implementing transition planning in IEPs of students aged 14 to 20.
 - Educate individuals, school systems, and service providers on the current state of the system in place to provide transition services to individuals with ASD.
 - Continue to develop and implement transition based services for individuals with ASD.
- Support the education and training of parents around long-term planning and support for their children with ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease wait-list time and increase availability/eligibility of services, such as diagnostics and mental health.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.
- Decrease the burden of cost for caregivers and families of an individual with ASD.
- Support a system to provide respite care for caregivers and families of an individual with ASD.

Ages 21+ (adult)

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Support the education and training of parents around long-term planning and support for their children with ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease wait-list time and increase availability/eligibility of services, such as diagnostics and mental health.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.
- Decrease the burden of cost for caregivers and families of an individual with ASD.
- Support a system to provide respite care for caregivers and families of an individual with ASD.

Diagnostics and Health

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Decrease the average age of initial evaluation and diagnosis for children with a concern of ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.
- Decrease wait-list time and increase availability/eligibility of services, such as diagnostics and mental health.
- Increase the system in place to provide services based on limited insurance coverage and provider preferences.

Training and Education

Goal: Study and evaluate issues related to scientific research, evidence-based and best practices in the field of autism and the development of a system of care that may come before the Council.

Objectives:

- Support the education and training of parents around adolescent development for children with ASD.
 - Develop and implement a system to teach independent living skills to adolescents with ASD.
- Support the education and training of parents around long-term planning and support for their children with ASD.
- Engage in a coordinated state-wide systems development and decrease fragmentation of service systems.

• Develop a system for parent education programs and state-wide dissemination of programs (i.e. telehealth network).

Regional Autism Network Directors

RAN Directors' Instructions: Consider the 10 identified objectives and incorporate into your legislated charge (see below).

- A staff that has expertise in autism and related disabilities.
- Individual and direct family assistance in the home, community, and school. A center's assistance may not supplant other responsibilities of state and local agencies, and each school district shall be responsible for providing an appropriate education program for clients of a center who are school age, inclusive of preschool special education.
- Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the family of the client, and the school district, and any other services that are appropriate.
- Professional training programs that include developing, providing, and evaluating preservice and
 inservice training in state-of-the-art practices for personnel who work with the populations served
 by the centers and their families.
- Public education programs to increase awareness of the public about autism and autistic-related disabilities.

Attachment B

Request for Funding Proposal

The Alabama Regional Autism Network (RAN) is a legislated organization under the Alabama Interagency Autism Coordinating Council (AIACC) through the Alabama Department of Mental Health that provides comprehensive care services for individuals with Autism Spectrum Disorder (ASD), their families, and providers that serve the ASD population, while also supporting the existing system of care that interfaces with the affected population. Funding for RAN currently totals at \$375,000 annually, and is divided among five university-based sites, with each site receiving \$75,000 annually. Sites are housed at the University of Alabama at Birmingham, Auburn University, the University of South Alabama, the University of Alabama, and the University of Alabama in Huntsville. The current funding allows for a Regional Director for each site, funded at .5 FTE, and additional staff positions or materials needed, which varies by site according to the needs of the region.

RAN legislation outlines the four charges and pillars of the network, and are required to be completed by each site according to the needs and resources present in the region. These four charges include individual and direct family assistance, technical assistance and consultation, professional training, and public education specific to the ASD population. RAN was able to expand services offered for each charge during the 2017-2018 fiscal year, during their second year of operation, and following the first year having all five sites funded and operational. In the last year, we were able to serve individuals in all 67 counties in Alabama. Major public education programs in the network currently include Coffee Chats and Community Education Workshops, which provide platforms for parents and caregivers to learn and discuss strategies for improving care for their children. Professional training programs, which occur on both a large and a small scale, educate professionals outside of the ASD field how to better care for this population, including, but not limited to, health care providers in the Black Belt region of Alabama, Children's of Alabama, statewide conferences for educators, and staff at libraries across the state. These programs will all help to make Alabama a more inclusive place for individuals with Autism.

However, while milestones and progress were made across all five sites in each of the four areas, additional funding for the Regional Autism Network would allow for increased outreach and service provision for the ASD population in Alabama. Primarily, increased funding would allow Regional Directors to increase their effort from .5 FTE, which would dramatically boost and enhance the outreach they can offer as an individual. It will provide directors with additional concentrated time allocated to the expansion of the network and support opportunities for increased collaborations among existing providers. Additionally, increased funding will aid in the expansion of the work conducted within each of the four charge and allow sites to hire additional staff with an expertise in ASD to increase outreach efforts and improve accessibility for individuals and families in the rural parts of the states that are isolated from services. This financial investment in RAN will allow for stronger support of the existing system of care and bolster proactive work across the state to reduce health disparities for the ASD population and promote health equity for all impacted by the disorder.

Collectively, the Alabama Regional Autism Network sites have identified the following areas in which additional funding would help to improve our services offered:

- Will allow for more travel to provide trainings across the state.
- Will enhance the ability to focus on geographically and socioeconomically underserved areas, which requires more time for travel and resources to provide trainings.
 - A focus on underserved areas will also require additional public awareness information (e.g., flyers, training materials, administrative supplies).
- Increased funding for Graduate Assistant positions will allow for additional training for earlycareer professionals with expertise in ASD, who can then go on to larger roles within the system of care in Alabama.
- Will allow for enhanced follow up with families through increased FTE for the Director and creation of GA positions.
- Will allow for increased collaboration and ability to meet with advocacy groups more frequently to address growing needs.
- Will allow for additional travel as needed, to include travel by constituency board members who reside in underserved areas.
- Will allow for the development of additional resources for families.

The surge in ASD diagnoses nationally and across the state necessitates immediate response from state legislators. Intervention is necessary to target the current barriers that individuals and families face when attempting to navigate the system and access to services, but additional prevention is needed to continue improving the system of care as the need for services increases. Investment in the expansion of programs and organizations, such as RAN, through additional funding and state level support will allow for effective change for the ASD population across the state of Alabama, making our state leaders at the national level as we work to advocate for this vulnerable population and improve long-term outcomes for individuals and families.